



Chapter 5

Delivering choice and control for disabled people

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Summary

Over the last decade, the Government has taken significant steps to improve rights and opportunities for disabled people. This is underpinned by our commitment that by 2025 disabled people will be respected and included as equal members of society with full opportunities to fulfil their potential.

To support this goal, we will consult on a series of possible further changes that would give disabled people greater choice and control over their lives, giving disabled people a right to request control over a range of public funding to which they are entitled, allowing them far greater choice over how best to spend this money so as to meet their needs.

The aim of these changes would be to ensure support is targeted to those who need it most, while increasing the independence and autonomy of disabled people. We recognise this is a major change so we will consult widely on the potential opportunities and challenges of a redistribution of power from the State to the individual.

Delivering equality for disabled people

- 5.1 In the last ten years, the Government has taken significant steps to improve rights and opportunities for disabled people. This is reflected in a commitment to equality for disabled people by 2025. This will ensure that disabled people will be respected and included as equal members of society, with full opportunities to fulfil their potential.
- 5.2 The reforms outlined in **Chapter 3** form part of a comprehensive strategy to address the severe disadvantages that disabled people can face in employment. In the past, incapacity benefits reflected an attitude which focused on what disabled people cannot do rather than what they can. This belongs firmly in the past. The proposals in this Green Paper are based on an understanding that welfare provision should support people to gain independence. This reflects disabled people's own wishes that they should be "*the experts in their own lives*".
- 5.3 In many areas disabled people now do have far greater control over the support that is available. The principle that people should be free to choose how to spend their benefits to meet their individual and family needs is already a feature, for example, of Disability Living Allowance. We introduced the Local Housing Allowance in Housing Benefit to give people more control over where they choose to live and how much to spend on rent.

- 5.8 The new local government framework, combined with £0.5 billion investment by the Department of Health is incentivising local government to modernise and personalise social care. These reforms are culminating in a new momentum at local level to work across the boundaries of care, housing and health, to give individuals more control over the support local government provides.
- 5.9 But there is still a long way to go, as the stories in **Box 5.1** show.

Box 5.1: Rose and Lucy's stories

"I want to be in the driving seat" – Rose's story

Rose has multiple sclerosis and is finding it increasingly difficult to walk. She is currently holding down her job as an office administrator but will require an electric wheelchair and some assistance to get to work if she is to continue. Aged 38, Rose has also had bouts of severe depression throughout her adult life and currently receives services from her local Community Mental Health Trust. In the current system, Rose will need to look to three different systems and sets of professionals to meet her needs. The Physical and Sensory Disability Team for her local authority will carry out an assessment of her needs while she is not at work; she will apply for support at work through the Access to Work programme; and her mental health support needs will be addressed by the Community Mental Health Team. She has already experienced some conflict between the three different sets of professionals involved as to who is responsible for what. Rose wants to be put in the driving seat of sorting out what support she needs in order to live an ordinary life.

"I could go from somebody very out in the world to somebody in my house all the time" – Lucy's story

Lucy has Osteogenesis Imperfecta, the more commonly used name for it is brittle bones. Lucy told us:

"I am academically able and I have a strong character and lots of friends. I went to school and university in the mainstream system and it worked well for me in terms of developing who I am as a young adult and the kind of aspirations I have for myself. I'm a development worker at the moment, for an organisation that builds capacity for other organisations to involve children and young people. I've had some really good professional support me, the kind that are on my side and who want me to be in charge. But then somebody took over my case who hasn't even met me and what they want is for me to have this very set timetable. There was no concern about the fact that I go from being somebody very out in the world and able to, kind of, interact with people to somebody that should just be in my house all day, every day, waiting for somebody to come and get me dressed, cook me food, turn on the telly and then put me to bed. What I would really like to see for the future is all professionals becoming allies and I and other people have that power."

Right to control

- 5.10 When people understand the resources that the State is prepared to spend to support them and are able to have an effective say in how those resources are spent, it can lead to a more satisfactory outcome for the citizen. It moves people from being under control, to in control, as active citizens. In Control was set up by the Department of Health and Mencap in 2003 to explore new ways in which people with learning disabilities could be given more choice and control in six local authorities. Evaluation of the first phase of In Control, between 2003 and 2005, found that almost three-quarters of those taking part believed they now had more choice and control over their own lives.
- 5.11 An evaluation of the individual budget pilot programme undertaken in 13 local authorities is expected later in the year. We want to explore how we might extend this by giving disabled adults greater control over the combined budget which the Government spends on their support. There are many models of individual budgets and programmes we could build on. We are keen to hear views about what steps the Government should take but we consider that a system to give disabled people greater choice and control – could include the following:
- the outcomes to be achieved from public resources should be agreed with the individual;
 - people should be told the resources available (expressed as an amount of money) to meet the agreed outcomes, and any shortfall should be made explicit;
 - people should have choice and control over how these resources are used in order to meet the agreed outcomes;
 - this process should cover as many of the individual's support needs as possible with the aim of preventing fragmented support plans that span across different agencies, budgets and programmes;
 - people should have access to advice and, where possible, be sign-posted to advocacy services if they need support to decide how best to use the resources available to them; and
 - safeguards so that public money is not abused.

Question 21: What are the next steps in enabling disabled people, reliably and easily, to access an individual budget if they want one? Should they include legislation to give people a right to ask for a budget or will the other levers the Government has got prove sufficient? What are the safeguards that should be built in? How can this be done?

- 5.12 We are piloting one model of individual budgets at the moment using six funding streams. We believe that we should consider whether this broad approach could be applied in other areas. So we want to explore the principles which could underpin the process in deciding which areas might be included and who should be covered. Possible principles might include the following:
- the funding streams should be subject to a needs assessment, rather than being universal services;
 - it should be possible to estimate a budget with reasonable reliability;
 - it must be possible to make the budget subject to an agreement about its use; and
 - any new system would be restricted to those disabled people already eligible for selected current funding streams.
- 5.13 We are interested in exploring how disabled people might receive a reliable and equitable service when requesting choice and control of the funds used to meet their needs, and whether public authorities could be expected not to unreasonably refuse such a request.
- 5.14 The National Health Service is shortly to begin piloting personal health budgets. Likewise, the Department for Children, Schools and Families and the Department of Health are shortly to begin piloting individual budgets in support of disabled children. Our aim would be to build on this innovative approach once we have reviewed the results and have a better understanding of the risks and benefits.
- 5.15 This would be a radical new approach and we will need to consider the implications carefully. This approach is one which could affect a huge number of citizens, central and local government and have an impact on providers in the voluntary and private sectors. We will want to involve disabled people and other stakeholder groups in developing these proposals. We have started this process by setting up an advisory group to help the Government chart the way forward. We will work with this group to consider the responses to this Green Paper. With their advice we will publish more detailed proposals later in the year.

Conclusion

- 5.16 For disabled people, support which they can direct themselves is an important requirement for equal citizenship. Each disabled person has their own ambitions and their own capability but too often they are not given an equal chance to realise them. The changes in this chapter emphasise our ongoing commitment to disabled people, ensuring that they receive support in a way that promotes independence, control and personal responsibility.